

10-1-2003

Beyond the Law: Life Stories and the Problem of Rights Among People with Disabilities

UB Law Forum

Follow this and additional works at: https://digitalcommons.law.buffalo.edu/ub_law_forum

Recommended Citation

UB Law Forum (2003) "Beyond the Law: Life Stories and the Problem of Rights Among People with Disabilities," *UB Law Forum*: Vol. 16 : No. 1 , Article 22.

Available at: https://digitalcommons.law.buffalo.edu/ub_law_forum/vol16/iss1/22

This Article is brought to you for free and open access by the Alumni Publications at Digital Commons @ University at Buffalo School of Law. It has been accepted for inclusion in UB Law Forum by an authorized editor of Digital Commons @ University at Buffalo School of Law. For more information, please contact law scholar@buffalo.edu.

Beyond the law

Life stories and the problem of rights among people with disabilities

A physical therapist with a learning disability switches jobs every few years rather than revealing his disability to an employer and requesting accommodations to which he is entitled by law.

A newspaper reporter in a wheelchair hesitates to "make waves" about the accommodations she needs in order to work effectively.

A paraplegic college student devises his own "accommodations" at university that include climbing a rope and entering through a window in order not to miss parties on the upper floors of his dormitory.

Those are just some of the stories in *Rights of Inclusion: Law and Identity in the Life Stories of Americans With Disabilities*. The new book, published by the University of Chicago Press, is the product of nearly a decade's work by UB Law Professor David M. Engel and Frank W. Munger, who recently left UB for New York Law School but who continues as an adjunct faculty member at UB and an affiliate of UB's Baldy Center for Law and Social Policy. The Baldy Center was a major supporter of the project, which was also funded by the National Science Foundation.

The book grew out of Engel and Munger's interest in the Americans with Disabilities Act at the time it was first enacted. They planned to explore how the rights conferred by that legislation played out in specific work settings. But as they conducted a series of focus groups among people with disabilities, Engel explains, the format of the research changed.

"We were talking about rights and the law in these focus groups," he says, "and what people kept leading us back to were their experiences growing up and



Chris H. Horan, a blind, second-year law student.

their experiences in school. Eventually we began to understand what they were saying — that law is relevant in terms of people's own concept of who they are, and who they are is really a factor of how their families raised them, how they grew up, and the extent to which they viewed themselves as someone who should be included or not. Rights appear relevant only to the person who assumes that inclusion is both possible and appropriate." The project soon shifted to

one that drew on individuals' life stories as the context for understanding how disability law actually functioned for its intended beneficiaries.

It was a major undertaking: From an initial pool of 180 people interviewed by telephone, the authors selected 60 for in-depth interviews aimed at understanding the role that rights play — or do not play — in the everyday lives of ordinary people. They also did in-depth follow-up interviews with six subjects, and took the unusual step of asking them to comment on the chapters written about them. The interviewees' comments and critiques appear in italics and are inserted throughout the authors' text.

The rights conferred by legislation, the authors say, become a reality in people's lives in several ways:

A few file complaints if their rights are abridged — but "nationwide, only a tiny fraction of people who could invoke the law generally do," Engel says.

Some are influenced by the cultural shifts that have accompanied the disability rights movement and the ADA: "In the 1990s, after passage of the ADA, people gradually began to talk about employment and inclusion differently," Engel says by way of example. "We think everyday discourse is extremely important. It makes rights seem relevant to someone who would not have seen them as relevant before. Once rights appear relevant, some people think about their lives and careers in much more expansive ways."

Institutional changes may take place

"We argue that rights do not just affect who people are and what they do ... we say that identity shapes law, just as law shapes identity." — Professor David M. Engel

that affect perceptions of what is available to people with disabilities. A number of those interviewed for *Rights of Inclusion* experienced an awakening when they left home for college – and found an array of accommodations, such as ramps, taping services and extra time for exams, that they did not know existed.

One of the most important findings was that the influence of rights dovetailed with individuals' perceptions of themselves – perceptions born, typically, in their family upbringing. Some people, who grew up thinking of their disability as an insurmountable obstacle, began to expect inclusion and employment when they discovered the accommodations available to them as a matter of right. Or they might not: "In the worst case, the law had almost zero effect on an individual," Munger says, "because that individual did not know about the rights or did not see their connection to her life circumstances." He refers to a woman with little education who suffered a stroke while working at a chicken processing plant. "For her, that was basically the end of her employment history," Munger says. "She stopped when the stroke laid her low. Rights never entered the picture."

An interesting aspect of the work is that some of those interviewed were aware of previous legislative and judicial efforts to ensure equal rights for racial minorities, such as the Civil Rights Act of 1964, and thought in those terms as they grappled with the issue of rights in their own lives. "That sometimes plays into their consciousness of their rights," Engel says.

Another provocative aspect, Munger points out, is that legal developments in

the appellate courts do not necessarily track with changes in society "at ground level." While the Supreme Court has been continually narrowing the reach of the Americans with Disabilities Act, "we are finding that in spite of that trend, the law is having an impact."

Summarizing the book's conclusion, Engel describes what the authors call "a recursive theory of rights." "We argue that rights do not just affect who people are and what they do," Engel says. "Law can certainly help to transform the identities of people with disabilities, but the result of new identities can be a new attitude toward the relevance of law and a new willingness to make rights become active in society. That is why we say that identity shapes law, just as law shapes identity." He cites the example of a young nurse with a learning disability. During a coffee break, her supervisor had said offhandedly that anyone who needed accommodations to pass the nursing exam was not fit to be a nurse. The nurse rebuked her supervisor and reminded her that she, too, had a learning disability and did her job very well.

"The woman we interviewed experienced a growing sense of self-confidence and an expectation of inclusion that was related to her consciousness of rights under the ADA. Even though she never made a formal legal claim, she began to use rights in conversations such as this, to adjust her relationship with her boss and change the way her boss thought about accommodations in the nursing exam," Engel says. "There is a back-and-forth quality to our theory of rights that is central to the way we think about it. But it is not necessarily an upward-and-onward kind of story. Sometimes rights do not become active. Their absence and omission also needs to be understood."



Rights of Inclusion: Law and Identity in the Life Stories of Americans With Disabilities. The new book, published by the University of Chicago Press, is the product of nearly a decade's work by UB Law Professor David M. Engel (top) and Frank W. Munger.